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SESSION IV: Progress towards implementation of ICD-10

**INTERNATIONAL HARMONISATION - ISSUES TO BE ADDRESSED FOR
MORTALITY AND MORBIDITY STATISTICS**

Invited paper submitted by the WHO Collaborating Centre for the
Classification of Diseases in the Nordic Countries and
the Swedish National Board of Health¹

International harmonisation of mortality and morbidity statistics is a topic that can be viewed from different perspectives. In this presentation we will mainly consider one aspect, namely the role of the International Classification of Diseases (ICD) as an important basis for international comparisons of mortality and morbidity statistics as well as for epidemiological research. In this field of research an international comparative approach is often used and needed. Only briefly we will mention some other issues related to international harmonisation in health statistics.

ICD -- an important tool for harmonisation

The International Classification of Diseases (ICD) has an impressive history of development which can be dated back to the 18th century. An international list of causes of death was formally adopted in 1893 by the International Statistical Institute as an instrument for international comparisons of mortality statistics. This international classification was

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subject for regular revisions every ten years.

While early revisions were concerned only with causes of death, the scope of the classification was extended to include non-fatal diseases from the Sixth Revision in 1948. It became a statistical classification used for the quantitative study of diseases, related morbid conditions, and death. The responsibility for the development, maintenance and improvement of the ICD was given to the World Health Organization (WHO) when the organization was created in 1948. WHO has been responsible for five major revisions of the ICD, the latest decided by the Tenth Revision Conference in 1989. The tabular list of The International Statistical Classification of Diseases and Related Health Problems -- which is the current name, with ICD-10 as the abbreviated title -- was published in 1992 and the alphabetical index in 1994 (1). The implementation process started in 1994 and is still on-going.

During the period of WHO's constitutionally-mandated responsibility for ICD it has become virtually universal in its acceptance as a standard statistical tool, essential at the international, national and local levels for the quantification of mortality, morbidity and related health problems. This development can be seen as a success story. ICD is an essential component of the statistical and several other WHO programmes at global and regional levels. Epidemiological and statistical analyses, many of them heavily dependent on data related to causes of death, injuries and diseases derived from the ICD, contribute significantly to the monitoring and evaluation of the world health situation and for the formulation of the strategy of the organization for the next century.

Thus, on a world-wide basis there has been a growth of the uses of ICD, spreading from the original need to classify causes of death on to indexing and retrieval of hospital records, to hospital and general morbidity studies. This has also produced a tremendous growth of the number of users of ICD. This broad international acceptance is the basis for the importance of ICD as a tool for harmonisation.

The possibility of updating ICD

An internationally accepted classification of diseases must have flexibility enough to concur with the development of medical science and at the same time exhibit stability and continuity over time. In earlier years WHO attempted to achieve this by revising the classification approximately every ten years, between which no changes were made. With the adoption of ICD-10, WHO accepted a new principle, however, making continuous updating

between revisions possible. This possibility entails greater flexibility at the same time as it may render comparisons over time more complicated.

The new updating mechanism has so far been used to a very limited extent and mainly for the purpose of correcting errors in the original version of ICD-10. WHO is currently working on the development of a procedure for the updating process and on the development of criteria for when updates are justified. The responsibility for the updating process is handled by WHO in collaboration with an existing network of WHO Collaborating Centres for the Classification of Diseases. This network consists of nine Collaborating Centres with primary responsibilities for ICD related matters in different language and/or geographical areas. The Heads of the Collaborating Centres have met annually for more than 25 years to provide advice to WHO on classification matters. Suggestions from national health statistical authorities for updating of the ICD should be channelled through the Collaborating Centres and are to be discussed in detail in a newly established Update Reference Committee before decisions are taken at the Centre Heads Meeting. Implementation of changes will take place nationally not later than 15 months after such a decision.

It is of course necessary to develop a system for global distribution of decisions regarding updates of the classification. Electronic communication has created new possibilities in this respect and updates will be published on the Internet as well as by other means.

It is too early to judge the importance of the updating possibility. Anyhow, it has the potential of increasing the flexibility of ICD in relation to the development of medical science. The credibility and acceptability of the ICD among the medical profession is to a great extent depending on how well the classification is able to reflect medical development. This, however, has to be carefully balanced against the need for statistical stability of the ICD.

Uniform application of rules and regulations

A very close adherence to the ICD structure and details is important when ICD is translated from the English "master version" to national versions in order to achieve international harmonisation in use. There are now some 35 national translations published and minor deviations from the original are by no means uncommon in national versions.

Not only is adherence to the details of the classification itself of importance for uniform use among countries; how the rules and recommendations for the use of ICD are applied is also essential. Some of these rules are embodied in the tabular list (Volume 1) and the alphabetic

index (Volume 3) but the most comprehensive collection of rules and recommendations related to the use of ICD for both mortality and morbidity statistics is to be found in Volume 2 (1). Unfortunately, these are not always translated into national versions.

Within mortality statistics -- the type of statistics most relevant for international comparisons -- it has become increasingly obvious that differences in the application of the classification rules for selection of underlying cause of death constitute the greatest threat to international comparability.

An e-mail discussion group on mortality coding

In 1996, the WHO Collaborating Centre for Classification of Diseases in the Nordic Countries took responsibility for the administration of an e-mail discussion group on ICD-10 mortality coding which was later named the Mortality Forum (2).

Questions related to the use of ICD-10 in mortality are sent to the moderator (Lars Age Johansson) who then forwards them to all members of the group. Comments and suggestions for coding are sent to the moderator who edits them and passes them on to the Forum once a week. The complete correspondence, with an index, is also made available on the homepages of the U.S. National Centre for Health Statistics (NCHS) and the Nordic Collaborating Centre.

The Forum has about 70 members at present, representing 36 countries. During the first year and a half 134 questions were received and some 500 comments were given. About a dozen countries have taken an active part in the discussion so far. On average, each question is discussed for six weeks.

The Forum has considered a wide variety of questions. Most of the questions refer to the application of the selection and modification rules for choosing the underlying cause of death. Some are on general principles for using ICD-10 and not specific to mortality coding, e.g. how to use Chapter XVI (conditions originating in the perinatal period), and how to interpret non-precise medical terms, e.g., tumour, immunosuppression. Others are on the rules and guidelines specific to mortality coding, e.g. what constitutes a highly improbable sequence of events reported by the certifier, which conditions are to be regarded by coders as ill-defined, and the rationale behind some of the coding instructions.

If anything, the Mortality Forum clearly demonstrates the need for international coordination of coding procedures. Even countries who pride

themselves on following the ICD instructions often code quite differently. Of the questions discussed at some length so far, there has been substantial disagreement on about half. Some of the problems might have little impact on international comparability, but there are still several cases where the coding differences discovered might cause epidemiologists serious trouble. Examples are the coding of "tumour" (which may influence statistics on cancer mortality) as well as how to code complications of diabetes and chronic obstructive pulmonary disease. In some other cases, differences in coding might cause noticeable, if not dramatic, discrepancies in the statistics.

Among those who have submitted comments, one might discern two different approaches to the ICD manuals: a "literalist" approach, where the coder follows the ICD manual to the letter, and an "intentionalist" approach, where the coder attempts to understand what the ICD wants to achieve with the coding instructions, and then codes accordingly. The literalist approach will certainly produce more consistent national statistics, but the coding becomes extremely dependent on the exact wording of the English version of the ICD. A literalist coding based on a translation of ICD-10 -- perhaps with an alphabetical index which is not based on Volume 3 of the English version -- could produce a different result. The intentionalist approach is not quite so dependent on the exact wording, but (as has been seen in the discussions) different countries may arrive at different interpretations. It seems, therefore, that none of these approaches is the ideal one, and that some type of agreed-upon compromise is needed.

Another classical problem also encountered in the discussions is the tension between rule-based coding and coding based on medical knowledge and experience. To the conscientious nosologist, coding arguments based on medical expertise and experience are neither here nor there. It is impossible for any person -- nosologist or physician -- to have an in-depth knowledge of all aspects of contemporary medicine, and coding based on personal medical experience is bound to be subjective and will vary considerably from person to person. In the interest of stable and comparable statistics, it is therefore preferable to base the coding on strictly observed rules. However, it is important that the coding instructions are, as far as possible, based on current medical consensus. If the gap between medical opinion and nosological procedures becomes too great, there is a substantial risk that the medical profession will eventually lose confidence in mortality statistics.

Members of the Forum very early expressed their concern that no decisions are taken -- the Forum just noted the differences, and/or that the ICD instruction on some point needs clarification. A procedure to arrive at an international consensus on how to interpret the instructions of the ICD was

therefore pro-posed to, and endorsed by, the Centre Heads Meeting in Copenhagen 1997 (3).

Following this suggestion, an international Mortality Reference Group is being established. Members are nosologists, physicians with experience in statistical classification of deaths, epidemiologists, statisticians with experience of production of mortality statistics, statistical analysts, and systems designers who understand the implications of the decisions for automated coding software. The mandate of the Mortality Reference Group is to make decisions on interpretation and application of the ICD. The group also identifies and suggests to the Update Reference Committee (mentioned earlier) possible updates (e.g. clarifications, changes, additions) to the ICD and its written rule system. The Update Reference Committee, which considers updates for both mortality and morbidity, will then present suggestions for updates to the annual Centre Heads Meeting.

Discussions in the Mortality Reference Group could form a link between intentionalists and literalists, and between nosologists and physicians, in that both intentionalist and medical arguments would be considered by the group, but once a decision has been reached, it should be applied literally. Thus, the establishment of the Mortality Forum and the Mortality Reference Group may turn out to be very effective instruments to achieve harmonisation of mortality statistics.

Automated coding of death certificates

The development of computer technology has opened up new possibilities to standardise the coding of causes of deaths. The first software available was the American ACME (Automated Classification of Medical Entities), developed by the National Center for Health Statistics (NCHS) in the late 1960s. ACME represents a major achievement in medical informatics.

Basically, ACME has two components: a logic which applies the ICD selection rules to the certificate, and large knowledge data bases, containing information on causes and complications of most conditions likely to be found on death certificates, and on ICD coding instructions specific to some particular cause of death. The coder enters an ICD code for each condition reported on the death certificate, and also states their position on it. ACME then applies the ICD coding rules and selects the underlying cause of death. In a next step, called TRANSAX (TRANSLation of medical AXis), the ICD coding instructions are applied to all other causes reported on the certificate.

While ACME and TRANSAX certainly standardised the selection of the underlying cause of death, they still relied on coders to assign an ICD

code to each condition, and the cost of mortality coding remained more or less the same. In the 1980s, the NCHS decided to develop MICAR, a software that automatically assigns ICD codes to the medical phrases found on the death certificate. While ACME and TRANSAX have become de facto international standards and form the nucleus of virtually all automated coding systems presently in use, most other countries have felt a need to develop software to replace or supplement MICAR, due to differences in administrative procedures, and -- most important -- language.

Experiences of automated coding show that it produces more consistent statistics, and is both feasible and potentially cost-effective. How cost-effective it is depends, of course, on the relative cost of typists and coders. With automated coding fewer coders are needed, but remaining coders will work mainly with complicated cases. Data entry costs will increase and might consume the savings made at the coding stage. That might be a disappearing problem, however, since many countries might eventually introduce electronic certification of death.

In Europe, automated coding systems are used or being developed in Catalonia, England, France, Italy, the Netherlands, Scotland, and Sweden. Several other countries are considering introducing it, not least since ICD-10 is far more complicated than previous revisions of the ICD and automated coding is seen as a help to overcome the difficulties. The European Community has also shown interest in automated coding, and a report on the matter was presented to EUROSTAT in June 1998 (4). The report recommends the use of automated coding as a means of improving the international comparability of mortality statistics, and -- to keep the comparability -- that coding systems are developed in close collaboration with other countries, using the knowledge data bases of ACME and TRANSAX.

The NCHS has also taken an important initiative in initiating an International Collaborative Effort (ICE) project on automated coding in 1996 (5). This will ensure international feedback on the on-going development and performance of the ICD-10 versions of MICAR, ACME, and TRANSAX, including the contents of the crucial knowledge data bases. This effort will surely strengthen their position as the international standard.

Harmonising coding in morbidity statistics

Much less effort has so far been put into the area of international harmonisation of morbidity than of mortality statistics. An obvious reason for this is that the difficulties are much greater for morbidity statistics. There is, however, a growing interest in comparisons between countries of, e.g., hospital discharge and other hospital activity

statistics. In hospital activity analysis clear rules for the selection of a main or principal diagnosis is of major importance.

ICD-9 contained for the first time guidance on recording and coding for morbidity and specifically for the selection of a single condition for presentation of morbidity statistics. The ICD-10 guidelines for the selection of a main condition for single condition analysis of episodes of health care has been further elaborated. The guidelines also emphasise that, where practicable, multiple condition coding and analysis should be undertaken to support routine statistics.

The dual classification scheme for etiology and manifestations -- known as the dagger and asterisk system -- which was introduced in ICD-9 has been the subject of a certain amount of criticism. Therefore, the dagger and asterisk system was revised and further developed in ICD-10. It seems clear, however, that countries differ with respect to how this dual system is implemented in the national versions of ICD-10. This, of course, adds to the difficulties of harmonisation, even if the dagger and asterisk system only applies to a small proportion of cases.

Resource related systems for grouping of hospital episodes -- based on or similar to the American system of Diagnosis Related Groups (DRGs) -- have been adopted in several European countries with minor or major modifications. These systems have been used both for case-mix analysis and for hospital reimbursement. While this use of hospital statistics probably mainly has contributed to more homogeneous coding among hospitals in individual countries, it may also have resulted in some international harmonisation due to the widespread use of DRGs. In this case, the American Clinical Modification of ICD (ICD9-CM) has often become the norm.

It remains to be seen which effect the development of DRGs will have when ICD-10 is implemented in the USA in the year 2000. Many European countries have implemented ICD-10 in the meantime and have been stimulated to develop their own resource related patient classification systems. This is true for the Nordic countries who have jointly developed the NordDRG system based on ICD-10 diagnostic coding and procedure codes from an independently developed Nordic Classification of Surgical Procedures (NCSP).

No international electronic discussion group -- corresponding to the Mortality Forum described above -- exists for the area of morbidity or hospital statistics. National groups have been established for discussion of hospital morbidity coding problems and DRG applications in the USA, Australia and the Nordic countries. It would be an important task for WHO and its Collaborating Centres to establish an electronic discussion network for morbidity-related classification and coding issues corresponding to the

Mortality Forum. This may be more complicated, however, since national differences in the application of rules may be greater in the area of morbidity as mentioned earlier.

Training and training material

Training of coders for both mortality and morbidity has traditionally been a national responsibility. There are great differences, however, with respect to the extent to which formal training has been available and for which groups of users training has been arranged. Coding of death certificates is centralised in most countries and therefore involves a relatively small number of coders. In contrast, clinical coding of hospital records involves many more persons and also different professions. In some countries medical record officers are responsible for hospital record abstracting and clinical coding, while in others this type of coding mainly is the responsibility of the physician in charge of the patient. The possibilities for formal training in coding for these groups are very different.

The introduction of ICD-10 prompted certain international training courses for mortality and morbidity coding arranged by WHO and some of the Collaborating Centres. Since these courses have been attended by coders, statisticians and physicians from different countries, they should contribute to international harmonisation of the use of ICD. Ideally, training courses should be available not only at the introduction of a new revision but also later when practical coding experience has been gathered.

Training material related to clinical coding has mainly been produced nationally because of language necessity (e.g. 6, 7). It is of course important that such material is made as uniform as possible in order to increase international comparability.

New computerised interactive teaching methods have been applied also to ICD coding. An example is TENDON, an interactive teaching programme for training in the use of ICD-10 for both mortality and morbidity (8). TENDON was developed in the UK and has later been translated into several other languages, e.g. French and Swedish. Greater use of such uniform, computerised training material could be a very cost-effective way of international harmonisation.

Statistical continuity problems in the use of ICD

The change from one classification revision to another by necessity entails great difficulties and the history of ICD shows different ways of overcoming these problems. One important feature is that only stepwise

changes have been made whereby the original overall classification structure has been left intact. In the change over to ICD-10, however, we face a relatively new situation. ICD-10 is the most extensive revision with far-reaching specifications which has nearly doubled the number of groups and codes. Certain chapters have been radically restructured and transfers have been made between chapters. In all, this has meant quite comprehensive changes in relation to ICD-9 and the Tenth revision therefore creates problems for the statistical continuity and comparability over time.

In addition, the implementation of ICD-10 has not been simultaneous in all countries, but is spread out over a fairly long period of time. Some countries implemented ICD-10 already in 1994. Full implementation of ICD-10 for mortality coding in all countries is not be expected to take place until about the year 2005. The concurrent use of ICD-9 and ICD-10 during as long a period of time as ten years creates great problems for the international comparability of statistics.

A traditional method for analysing the effects of a classification shift is the so-called bridge coding method. This means that the same basic material (death certificates or hospital discharge abstracts) is coded twice, first according to the old revision and then -- independently -- according to the new revision. By comparing the results in statistical tables by chapters or other large groups or even certain diagnoses, one can gather insight into the significance of the classification change itself. Thus, correction factors can be calculated and used to compensate for the classification shift when comparing statistics based on data coded according to different revisions.

A number of such studies have been carried out in connection with previous classification shifts and there are plans for carrying out such studies on the effect also of the shift to ICD-10 (9-11). The advantage of this method is that it does not only capture changes in the classification itself but also reflects changes in the rules for its application. It is, however, a time-consuming and resource-intensive method and it is not certain that the results from a bridge coding study in one country can be applied to another country due to the national divergences in how rules and guidelines are used.

The use of equivalence tables

The situation of today with highly computerised medical documentation, stored in longitudinally arranged data bases, leads to requests for methods to overcome continuity breaks. Health statistics authorities often receive requests for computerised methods that automatically convert all earlier registered information to the codes of the new classification or methods

that prospectively code new information also according to the codes of the earlier classification. Thus, the interest and anticipation for some kind of translation tables have been great but often quite unrealistic.

At earlier classification shifts WHO has published so-called equivalence tables between the two sets of codes. Early in 1998 WHO also made available a set of diskettes with code files and a presentation programme called Translator (12). The files were based on earlier work at the UK Collaborating Centre (13) and comprise equivalence tables on the most detailed level between ICD-9 and ICD-10 and vice versa. For instance, for each specific ICD-9 code all the codes in ICD-10 that completely or partly correspond to this code are presented with a relation code. The relation code indicates if there is a one-to-one relation, a one-to-many relation, a many-to-one relation or a many-to-many relation. Some ICD-10 codes represent new conditions that did not exist in ICD-9. Also, the expansion of the dagger and asterisk system has lead to a number of asterisk codes in ICD-10 which have no corresponding codes in ICD-9.

The equivalence tables may be very useful for researchers who want to find out exactly what may have happened to the coding of a certain condition, the occurrence of which one wants to follow over time. The tables do not, however, solve the practical statistical problems of comparisons across the classification shift in an easy way. The use of the tables requires a thorough knowledge of the two classifications. As mentioned earlier, the equivalence tables do not reflect consequences of changes in selection and modification rules.

A possible further development of equivalence tables is some type of practical translation table which would indicate the most likely or most frequent equivalent code in cases when the equivalence table gives several alternative corresponding codes. Such a translation table would, of course, only be approximate and this must be pointed out to users. It is a problem, however, that users tend to disregard such reservations. There is some experience from using this type of translation tables in countries where one has tried to apply ICD9-CM based DRGs to data coded by ICD-10.

Short tabulation lists

Most statistical analyses require some form of a short tabulation list and such lists have been presented with each revision of ICD for international comparisons. There is, however, a lack of continuity between lists related to different revisions, since they are usually based on the new revision only and on present epidemiological considerations. It should be possible also to construct short lists that are influenced by a wish to compare data across classification shifts.

The Nordic Medico-Statistical Committee (NOMESCO) publishes health statistics from the Nordic countries yearly. For inter-Nordic comparisons NOMESCO has developed a Nordic abbreviated list of causes of death, consisting of 52 groups. This list has been defined in relation to ICD-8, ICD-9 and ICD-10. The list has also had an influence on a corresponding European list developed by EUROSTAT. In its latest publication NOMESCO has made use of a Nordic short list for hospital morbidity (60 groups) defined in relation to both ICD-9 and ICD-10 (14).

These abbreviated lists for inter-Nordic comparison have been of practical importance, since the Nordic countries did not implement ICD-10 simultaneously. In addition, the Nordic countries use abbreviated lists for continuity within their national statistics. An example is a Swedish hospital morbidity tabulation list of 99 diagnostic groups defined according to ICD-7, ICD-8 and ICD-9.

It must be recognised that the comparability is not perfect but such lists have been found to be of practical use. Even for these purposes one would need bridge coding in order to analyse more exactly how well the translation has worked

Thus, work on short tabulation lists has so far mainly concentrated on defining diagnostic groups from the perspective of epidemiological interest rather than from the perspective of practically attainable comparability. An urgent task for the long period of transition between ICD-9 and ICD-10 would be to develop international short tabulation lists which optimise the possibility for comparisons between ICD-9 and ICD-10 coded data. This probably means that we have to abandon the requirement of complete coverage and concentrate on a limited number of groups of high significance where a reasonable degree of comparability can be achieved. Such lists may be called co-ordinated short tabulation lists. This seems to be an important task for WHO, which cannot very well continue to publish mortality statistics from different countries in the World Health Statistics Annual according to ICD-9 and ICD-10 in parallel but incomparable series.

Other health related classifications

Work on other health related classifications beside ICD should also be considered as an issue for harmonisation of morbidity statistics, such as classifications of therapeutic, diagnostic and other procedures in medicine. WHO published the International Classification of Procedures in Medicine (ICPM) in 1978 (15). It was adopted only by a few countries and has never been revised.

Many countries or groups of countries, such as the Nordic group, have developed and recently revised their own classifications of surgical operations and other procedures (e.g. 16). Therefore, it has been deemed neither meaningful nor possible for WHO to develop a new international classification of procedures. WHO should, however, continue its role as a clearing-house for information on available national procedure classifications. The development of an international short tabulation list consisting of common and important procedures should be an important task for WHO and its Collaborating Centres. The list does not need to be comprehensive and cover all surgical activities. Further, taxonomic work is necessary in order to define such a list in relation to existing procedure classifications.

Surgical and some medical procedures are important characteristics in addition to diagnoses for patient classification systems like DRG. The difficulties in making case-mix systems internationally comparable is to a certain extent depending on the lack of a generally accepted classification of procedures.

Other issues and concluding remarks

The issue of international harmonisation can be viewed from a much broader perspective than the classification approach dominating this paper. A relevant question concerns methods for age standardisation. There are examples from published international mortality statistics where the standardisation methods used have not been clearly described. Premature changes of standard populations have also been made which have hampered comparability over time.

Publication of primary data with detailed enough age groups is perhaps the most important way to overcome these difficulties. This allows users to carry out their own standardisation relevant to the comparisons wanted. This detailed tabulation should be done in addition to publication of standardised data with a clear description of the method chosen. Such a policy should not be too cumbersome when traditional publications can be supplemented with electronic accessibility.

This paper emphasises the importance of ICD and other health related classifications as means for harmonisation of mortality and morbidity statistics. One important message is the need to study and understand how diverging applications of the classification may influence international comparability. Another message is the need to facilitate the shift from ICD-9 to ICD-10. In the paper, we have given examples of how difficulties may be overcome or reduced in these two areas. The paper thus indicates ways to improve international comparability in health statistics.

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